

My name is Dr Jim Reynolds. I am a pediatrician and a medical geneticist and a Fellow of the American Academy of Pediatrics and the American College of Medical Genetics. I wish to speak in support of SB 162.

In the United States, newborn screening is a highly visible and important state based public health program that has been in existence for more than 40 yrs.

1. There are no national standards and this has resulted in significant disparities in screening services available to infants in different states for potentially serious medical conditions which are treatable.
2. At the request of the Maternal and Child Health Bureau of the Health Resources and Services Administration, the American College of Medical Genetics convened an expert panel on newborn screening and recommended mandatory testing for 29 conditions; a hearing screening and 28 inherited metabolic and other disorders. These recommendations have been endorsed by the American Academy of Pediatrics and the Montana Chapter of the Academy.
3. The conditions screened for meet the following criteria:
 - identified at a time (24-48 hrs after birth) at which it would not ordinarily be detected clinically.
 - the test has appropriate sensitivity and specificity.
 - there are demonstrated benefits of early detection, timely intervention, and efficacious treatment of the condition.
4. Cystic Fibrosis is one of the recommended conditions to test for:
 - the most common life-limiting autosomal recessive disorder in Caucasians.
 - 1 in 25 Caucasians are carriers.
 - 4 Montana children are born each year with Cystic Fibrosis.
 - early identification (prior to age 2 mos) results in increased survival, reduced costs, fewer hospitalizations and fewer complications over a lifetime.

Montana law currently mandates testing for Phenylketonuria, Galactosemia, hypothyroidism, and hemoglobinopathy.

1. Some newborn children in Montana are tested for only these disorders while others receive the full panel of 28 tests.
2. The only way to ensure that all Montana babies are screened for all of these life-threatening disorders is to mandate the testing as outlined in SB 162.

Newborn screening is more than testing. It is a coordinated comprehensive system consisting of education, screening, follow-up contact, diagnosis, treatment and management, and program evaluation.

1. Currently Montana does not have a coordinated, comprehensive system.
2. SB 162 would mandate such a system.